

# PREEMIES TODAY

*Families Helping Families*

## Preemie of the Month: Abigail Hull

A Little Girl with Big Challenges Continues to Grow and Learn

by Patty Hull

**M**icro preemie is such a loaded word. It's a word that has no meaning to most people and yet can summon waves of emotions in others. Our story is probably very similar to many other preemie stories. However, there are no two preemies that have experienced the same journey.

My first pregnancy had seemed very healthy, except for the constant nausea and frequent vomiting. I continued working as an RN in a labor and delivery unit at a nearby hospital and enjoying life with my husband. Our world was shaken when I reached 23 weeks. I experienced unexpected contractions resulting in an ambulance ride to a high risk OB unit. After taking one look at the doctor's face upon being examined and hearing a quiet profanity come from his mouth,



I knew without a doubt something was very wrong. My heart fell to my stomach and I felt like I was going to be sick. Magnesium sulfate, betamethasone, ampicillin, gentamycin, vancomycin, and trandellenburg position were all terms I was familiar with from working as a nurse. However,

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these medical words seemed much more serious as they referred to me and my condition since I was the patient this time.

After a horrendously long night of vomiting, contracting, shaking and worrying I was rushed into the OR for an emergency c-section to deliver my extremely premature daughter before she kicked her way out. We were told that

she had a very small chance of survival. I heard a short, very tiny cry before I was put under due to unbearable pain caused by the surgery.

I couldn't believe my daughter was born--she was no longer protected inside of me. The first time I saw her, the NICU scene took my breath away. All I could do was weep and wish I could put her back. Standing there beside her warming bed in the NICU I knew we had started a difficult journey, but never realized just how emotionally challenging the trip would be.

Abigail Christina was born at 23 weeks and 4 days gestation. She weighed 1lb 5ozs and was 11 ¾ inches long. I had never seen such a tiny baby alive. Yet there she was before my eyes, moving her wee arms and kicking the saran wrap that covered her warming bed. I will never forget the connection we made when I touched her little foot as it met the wrapping. We couldn't touch her because her skin and neurological system was too delicate and immature. Everything about Abby was immature. Her eyes were fused shut; her ears were just skin and easily folded into her face after lying on her side. Despite all of these qualities she was so perfect! Her hair was velvety soft and very dark. Her eyelashes were long and beautiful. My husband, Patrick, and I just sat by her bed day after day watching her, praying for her recovery, and waiting for something to change. We waited for her to improve or for her body to tell us she didn't want to fight anymore.

With every battle the doctors explained how critical Abby's condition was, and warned us to be prepared to make a decision about her life support. We were completely weak from fear, from crying, and from all the uncertainty. All we could do was cry out to God, asking for her complete healing and for strength to make the right decisions for her life.

See Abigail Hull, page 5

**Preemies Today**  
P.O. Box 523525  
Springfield, VA 22152

**Founded:**  
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**web:**  
[www.preemiestoday.org](http://www.preemiestoday.org)

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**Preemies Today** is a 501(c)3 non-profit organization whose mission is to reach out and provide support to families of infants born prematurely beginning at birth and throughout childhood.

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## Calendar of Events

### September

**Annual Meeting**  
**Under the Sea Family Event**  
**September 8, 2:30 pm**  
Tysons Pimmet Library, Falls Church, VA

**Parent Support Meeting**  
**September 12, 7:30 pm**  
Barnes & Nobles, Fair Lakes, VA

### October

**Parent Support Meeting**  
**October 10, 7:30 pm**  
Barnes & Nobles, Fair Lakes, VA

**Halloween Spootacular Event**  
**October 27, 1:30 pm**  
Burke Lake Park, Burke, VA

### Mailbag

Please send us any feedback, suggestions, comments, or contributions including poems, high calorie recipes, or articles for the next issue to:

**[info@preemiestoday.org](mailto:info@preemiestoday.org)**

Preemies Today Newsletter  
P.O. Box 523525  
Springfield, VA 22152

***Are you interested in joining a playgroup?***  
contact Julie Kipers at  
**[juliekipers@preemiestoday.org](mailto:juliekipers@preemiestoday.org)**

# Program Updates

## Best Wishes To Our Departing Board Members:

**Ashley Hall** has been a great contributor to the Premies Today Board. Her expertise in computer programming is going to enable her to enhance our current database system. The Team Katelyn/Premies Today Golf Tournament raised over 27,000 and Ashley has lent us her knowledge and experience with raising funds and hosting large events. Ashley has also been very interested in parent support and is the coordinator of the Leesburg Playgroup.

**Deborah Leaf** is an original member of the Premies Today Board of Directors. She has worn many hats during the last four years. She has been Playgroup Coordinator, Support Group Leader, Secretary, Treasurer, and Newsletter Editor. She has left a lasting impression on this organization and plans to continue to volunteer for Premies Today to help support families. Deborah is a nurse practitioner who recently went back to work with developmentally disabled adults in a group home last January.

**Julie Kipers** has been part of the Premies Today since its inception in 2003. She has been instrumental in her work with the Premies Today website. She did the original design and later took the role as Premies Today liaison in working the redesign with the website design company NolaFlash. Julie also manages the Yahoogroup and handles the membership database. This past year Julie obtained a \$1,000 grant for Premies Today from her company LMI to be used for parent support and education. If all this was not enough, Julie was our organization's Secretary who took amazing notes at our Board Meetings. Julie plans to continue to volunteer for Premies Today as Playgroup Coordinator and taking the lead for supporting parents with school-aged premies

**Next month we will be introducing our new Board Members.**

SALE! SALE! SALE!  
*White House Ornaments!*

**-Don't Miss Out - \$20**

**All Proceeds to Benefit the Holidays in the NICU Project**

Contact: **Elaine Noto** at [elainenoto@premiestoday.org](mailto:elainenoto@premiestoday.org)

### Premies Today Membership

Year	2004	2005	2006	2007
Member Totals	22	97	150	350

### What We Do:

We offer local in-person support to families of premies in the extended Washington DC metropolitan area. We provide on-line support to families of premies located across the country and internationally.

### Programs:

- Monthly Newsletter
- Parent Support Meetings
- NICU Premie Care Packages
- Telephone Hotline
- Play Groups
- Family Outings
- Parent Education
- Resources Brochures
- Yahoo Group
- Online Chat

## Call For Volunteers!

If you are interested in volunteering for Premies Today please email us at [info@premiestoday.org](mailto:info@premiestoday.org)  
 Volunteer hours are flexible and can fit your schedule. As our organization continues to grow so does our need for volunteers.

## Join Our Yahoogroup!

### Subscribe:

<http://groups.yahoo.com/group/PreemiesToday/>

Meet wonderful parents from the DC metropolitan area as well as elsewhere in the United States.

# Choosing the Right Pediatrician

by Lynn Kuba, RN

**D**uring your baby's NICU stay, it is important to choose a pediatrician so there is a smooth transition of care for your baby after discharge. You may ask your baby's NICU doctors and nurses for a few referrals by bringing in your insurance's approved list of providers. It is important to interview a few pediatric practices either in person or by phone in order to choose one that is best suited for you and your baby (or babies). **Make a list of your most important questions before your interview.** Here are some questions to help you get started:

- ♦ Is the pediatric practice accepting new patients? Do they accept your method of payment, e.g. insurance plan, HMO or Medicaid? What is your co-pay?
- ♦ Are they experienced with NICU graduates and your baby's particular medical and developmental needs, e.g. premies, multiples, a certain syndrome or medical condition? Will they routinely make a longer appointment to meet your baby's needs?
- ♦ Do the doctors have specialty areas of training? Are they board certified? How many years have they been in practice? Are they familiar with your baby's specialists?
- ♦ Who is on their staff, e.g. physicians, registered nurses, nurse practitioners, others? Are there any other doctors that are used "on-call?" Do they have any other office services?
- ♦ Are they conveniently located for scheduled and urgent appointments? Is there more than one location? What are their office hours? Do they have same day appointments and weekend hours? How do they schedule routine and urgent appointments?

- ♦ How is the office set-up? Separate "sick" and "well-baby" waiting areas? What is a typical wait time for a scheduled appointment? Where would your NICU grad wait?
- ♦ Who answers their phone during office hours and after hours? Are there charges for after-hours calls? How are messages handled? Is there a call-in phone time so that you may speak to a nurse or doctor? Do they have a website or e-mail communications?
- ♦ What hospitals do they have admitting privileges or affiliations with? In an emergency, to which hospital would they refer your baby, e.g. a children's hospital or the closest one?
- ♦ What are important issues for you and your baby, e.g. feedings, medications, medical treatments, immunizations, early intervention, sleep habits, siblings, childcare, cultural or religious issues? Are the doctors' and nurses' views supportive?
- ♦ What are your overall impressions of this practice, e.g. philosophy, office environment, office staff, services and communication styles? Would you feel comfortable taking your baby there as well as calling for routine care, urgent care and referrals?
- ♦ How soon and how frequently would they see your baby for follow-up?

**Please call in advance and make an appointment with your baby's pediatrician for 1-2 days after discharge from the NICU.**

## School Days !

### Back to School Tips for Parents of School-Age Children

**Whether your premie is starting day care for the first time or heading back to school, here are a few tips to start the year off right!**

1. Have your child get plenty of rest.
2. Find the best way to communicate with your child's teacher or therapists. If possible obtain e-mail addresses for easier communication, or have a communication notebook in your child's backpack.
3. Schedule a conference with your child's teacher during the first few weeks.
4. If your infant premie has a school-age sibling have them change clothes as soon as they get home from school.
5. Read with your child daily.
6. Check your child's backpack everyday.

# Preemie Update: My Hero *by Jenna Briganti*

Smart, imaginative, entertaining, and charismatic are all adjectives that, 4 ½ years ago, I didn't even dare to imagine could one day describe my tiny son.

Vincent was born at just 28 weeks and 2 ½ lbs, but even that seemed more than I could have ever hoped for. When my water broke at 22 weeks, I wasn't given much hope for my baby. I was told to expect the best but prepare for the worst. I did expect the best and that is exactly what I got. Vincent was born breathing on his own with no need for a ventilator, CPAP, or even supplemental oxygen. He sailed through his 49 days in the NICU and came home at 7 weeks old, 35 weeks gestation, and just under 5lbs.

We did experience some normal preemie problems while in the hospital, but nothing with lasting effects. Vincent quickly caught up and was walking by 17 months. He was eating with a fork and spoon by 20 months and speaking in full sentences with a wide vocabulary by 2 years. Everyone we met was surprised that this child could have ever been a preemie, especially a preemie born 12 weeks early!



During October of 2006 when Vincent was 3 ½, his former preemie status seemed to show itself again. Vincent came down with a very severe pneumonia that we now think was caused by aspirating particles of vomit into his somewhat preemie-compromised lungs. Within a period of four hours he was intubated and put on a helicopter bound for the Fairfax PICU. I was in complete shock! This was my healthy boy. He wasn't a preemie anymore and things like this were not supposed to happen. After a week long stay in the hospital, a few new diagnoses, and a shell-shocked mom and dad, we were on our way home to begin the emotional recovery of what seemed to take more of a toll on us than Vincent's actual birth.

Vincent is once again my healthy boy. He's 4 ½ now and beginning to read. He is incredibly smart, observant, energetic, and hilarious. He never fails to surprise me, to make me laugh, or to melt my heart. I'd like to think that our family can move on and put the traumatic events of his birth and his recent illness behind us. I believe Vincent will always be my little preemie--more importantly, I know he'll always be my little hero.

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## Abigail, continued from page 1

Fortunately Abby continued fighting through every difficulty. She fought more battles than most people have to face in a lifetime. Some of them included a grade IV intraventricular hemorrhage, hydrocephalus, bleeding in her lungs, necrotizing enterocolitis with bowel perforations (twice), ileostomy, retinopathy of prematurity leading to retinal detachments, bronchopulmonary dysplasia, and reflux. The list goes on and on. Abby spent 185 days in the NICU at East Tennessee Children's Hospital. I've recently heard of something called "NICU Psychosis," where parents start to go a "little nuts" after being in the NICU for so long--I know we experienced this!

Our struggle didn't end when we left the NICU. Some babies are very fortunate to have graduated from the preemie experience with mostly memories of their early days. Our sweet daughter will always carry the effects of her prematurity. Her life and her challenges have added a dimension of joy and privilege that I never knew existed. We live in the world of post prematurity and always will. With this world comes heartache in realizing and accepting our child has serious disabilities, but also incredible celebrations when she makes progress. Even the smallest improvements in her life are mountain peaks reached for our family.

*"I like to hear people refer to children like Abby as differently-abled."*

I like to hear people refer to children like Abby as "differently-abled." Abby sees with her hands instead of her eyes and she hears with the assistance of hearing aides. She is nourished through a feeding tube, but loves to taste a sweet lollipop. Abby isn't walking yet, so we are blessed with extra time to cuddle. We have invested our resources into special therapy which gives me large blocks of time alone with her. She loves the water and enjoyed being in the pool during our recent family vacation to Florida. She also likes to play with her younger brother, Joshua, while he wrestles with her. Because Abby looks different than other children her age, we have had many precious opportunities to meet other children and their families who are "differently-abled" as well.

We know that God has used Abby to touch others. Hundreds of friends and family feel connected to Abby and to our family because they prayed for her when she was sick. Special friendships have developed because Abby is in our lives and we cherish them. There are still many days of tearfulness when emotions are raw and we feel weary. Through it all we believe God's grace is sufficient to meet all of our needs, even when we feel broken. God has a purpose for Abby's life and we look forward to seeing that purpose unfold.



# Thank you...

## Ink Recycling Company Donates to Premies Today

by Al Miller

Our son Jason, a 34-weeker, turned 2 in June, 2007. We have been especially blessed, as most of his preemie related health issues have been relatively minor. We're still working on some sensory issues and improving his coordination and muscle tone, but for the most part we consider ourselves very lucky. Over the past two years, **Premies Today members have been a great source of assistance, knowledge, and support to our family.**

About a year ago, I got involved with a group called **Recycling For Charities (RFC)**. The group helps the community and the environment by arranging with local companies to pickup and recycle their used fax, inkjet and laser cartridges. A significant portion of the proceeds are then donated to local community organizations.

I selected Premies Today as the charity for my efforts with RFC. Premies Today is our family's primary volunteer effort and it seemed like a natural fit. I also saw it as a great opportunity to give back to the organization for all it has done for our family. Over the past year, RFC has donated

over **\$2,000 to Premies Today**, which we hope will assist in the group's numerous programs to help out other premature infants and their families.

In addition to the obvious monetary benefits for Premies Today, the recycling of these cartridges is very important for the environment; every year millions of pounds of fax, inkjet, and laser cartridges are disposed of in our landfills. RFC's recycling efforts helps keep many of these items out of the landfills. We typically work with businesses in the Washington D.C. metro area and collect anywhere from a few boxes to a few pallets at a time. If you know of a company or group who currently isn't recycling their used cartridges and would like to help out Premies Today and other charities in the process, please feel free to contact Al and Stephanie Miller at [laxtodca@hotmail.com](mailto:laxtodca@hotmail.com).

***Premies Today would like to thank Al and Stephanie Miller for their donation and the time and effort that they have put toward volunteering for Premies Today.***



# Local News...

## Preemies Today Receives Award from the March of Dimes

**Premies Today** received an award for being the **#1 Family Team in Fairfax County** for raising over \$39,000. Ashley and Michael Hall's Team Katelyn were major contributors and raised \$28,000. Congratulations to all for contributing to the March of Dimes's mission to reduce the number of birth defects and premature births in the United States. Money raised in the Walk America campaign goes toward the mission of the March of Dimes to help prevent and reduce the number of birth defects and premature births in the United States.

*Join the 2008 Premies Today Walk America team*  
Contact us at [info@premiestoday.org](mailto:info@premiestoday.org) to find out more.

**October 25**

## **Pete and Pam Wright Special Education Law and Advocacy Workshop**

8:30 am to 4:30 pm  
McLean Bible Church

For more information or to register go to the Autism Society of America Northern VA Chapter website at [www.asanv.org](http://www.asanv.org)

# Helpful Resources

## Websites and Numbers

**March of Dimes**.....[www.marchofdimes.com](http://www.marchofdimes.com)  
The March of Dimes offers a wealth of information about preterm labor and premature birth.

**Social Security Administration**.....[www.ssa.org](http://www.ssa.org)  
Many premature infants qualify for Social Security Disability regardless of income. Go to the above website to find your states program.

**State Children Health Insurance Program (SCHIP)**.....[www.insurekidsnow.gov](http://www.insurekidsnow.gov)  
All states have a health insurance program for uninsured families that meet the income gap. Go to your state's program.

**Sidelines National Support**....[www.sidelines.org](http://www.sidelines.org)  
Sidelines provides support for pregnant women on bedrest and those dealing with the after effects of bedrest.

## Social Services

### Virginia

Alexandria- (703) 838-0700  
Arlington- (703) 228-1550  
Fairfax County- (703) 324-7500  
Fauquier County- (540)347-2316  
Loudoun County- (703)777-0353  
Manassas City- (703)361-8277  
Manassas Park-(703)335-8898  
Prince William County- (703)792-7500

### Washington DC

Department of Human Services  
(202) 671-4200

### Maryland

Montgomery County (240) 777-1245  
Prince George's County- (301)909-7025

**For more resources  
go to [www.preemiestoday.org](http://www.preemiestoday.org)**

## Early Intervention

*This is a federally mandated program available in every state to screen and treat children under the age of 3 for developmental disabilities and delays. If you have any concerns about your preemie's development, contact your local office to have your child tested. Services are covered by most insurances and are billed on a sliding scale.*

### Virginia

Infant and Toddler Connection  
Alexandria- (703) 838-5060  
Arlington County- (703) 228-1630  
Fairfax County/Falls Church- (703) 246-7121  
Loudoun County- (703)-777-0561  
Prince William- (703) 792-7879

### Washington, DC

Office of Infants and Toddlers With Disabilities  
(202)727-8300

### Maryland

Infant and Toddlers  
Montgomery County- (240) 777-3997  
Prince George's County-(301) 265-8415

## Women Infants & Children (WIC)

*The WIC program provides food vouchers and nutrition counseling services to low-income women and children.*

### Virginia

Arlington- (703) 228-1260  
Alexandria- (703) 838-4879  
Manassas- (703) 792-4703  
Woodbridge- (703) 792-7319  
Springfield- (703) 569-1031  
Mount Vernon- (703) 660-7100  
Fairfax- (703) 246-7100

**Washington DC - (202) 645-5662**

### Maryland

Montgomery County (301) 762-9426  
Prince George's County (301)856-9600

## **Membership/Subscription Information:**

We offer the Preemies Today newsletter, family outings, parent support groups, preemie play-groups, and “A Friend to Talk To,” our call-in line, for parents and families of preemies. Membership in our organization is free.

For a free subscription to our newsletter and to join Preemies Today please email us at [info@preemiestoday.org](mailto:info@preemiestoday.org) or you may go to our website at [www.PreemiesToday.org](http://www.PreemiesToday.org) and click on “Join us.”

This newsletter was funded by a Community Grant from the March of Dimes. This material is for informational purposes only and does not constitute medical advice. The opinions expressed in this material are those of the author(s) and do not necessarily reflect the views of the March of Dimes.

## **Don't Miss These Events!**

### **Annual Meeting**

September 8, 2:30 pm, Tysons Pimmet Library

### **Support Meeting**

September 12, 7:30 pm, Barnes & Nobles Fair Lakes

### **Halloween Spooctacular**

October 27, 1:30 pm, Burke Lake Park

***Please RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)***

**PREEMIES  
TODAY**

P. O. Box 523525  
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Do you need to talk to someone who understands the preemie experience? If so, call the “Friend to Talk to” line at  
**1-888-712-3208**  
or  
**703-552-0163**